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ABSTRACT

This brochure summarizes content that is covered in the DO-IT 17-minute videotape, "Taking Charge: Stories of Success and Self-Determination." The document provides insights from successful young people and adults with disabilities associated with the DO-IT project. These insights are designed to help young people with disabilities learn to lead self-determined lives. The publication begins by defining self-determination as a combination of skills, knowledge, and beliefs that enable the person to engage in goal-directed, self-regulated, autonomous behavior. Self-determination insights organized around advice synthesized from hundreds of responses of the successful young people and adults with disabilities who contributed are then identified: (1) define success for yourself; (2) set personal, academic, and career goals and keep your expectations high; (3) understand your abilities and disabilities and play to your strengths; (4) develop strategies to meet your goals; (5) use technology as an empowering tool; (6) work hard, persevere, and be flexible; and (7) develop a support network and look to family, friends, and teachers for support. (CR)

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Taking Charge: Stories of Success and Self-Determination

Sheryl Burgstahler

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Taking Charge: Stories of Success and Self-Determination

DO-IT

By Sheryl Burgstahler, Ph.D.

We often hear about the problems young people with disabilities face – physical obstacles, social rejection, academic failure, and medical crises. Yet some people do overcome significant challenges and lead successful lives. What does "success" mean to them and how do they achieve it? What internal characteristics do these individuals possess and what external factors have been present in their lives? What advice do they have to help young people build personal strengths to overcome the challenges they no doubt will face?

Included in this brochure are insights from successful young people and adults with disabilities associated with the DO-IT project. These insights may help young people learn to lead self-determined lives. But, what is self-determination? There are many definitions to choose from. The following definition is concise and incorporates a number of common themes found in other definitions.

> *Self-determination is a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults.* (Field et al., 1998, p. 115)

Gaining control over your life involves learning and then successfully applying a number of self-determination skills, such as goal-setting, understanding your abilities and disabilities, problem-solving, and self-advocacy. The personal process of learning, using, and self-evaluating these skills in a variety of settings is at the heart of self-determination.

The content of this publication is organized around the following advice synthesized from hundreds of responses of the successful young people and adults with disabilities who contributed:

1. Define success for yourself.
2. Set personal, academic, and career goals. Keep your expectations high.
3. Understand your abilities and disabilities. Play to your strengths.
4. Develop strategies to meet your goals.
5. Use technology as an empowering tool.
6. Work hard. Persevere. Be flexible.
7. Develop a support network. Look to family, friends, and teachers.

Perhaps young people with disabilities will find the experiences of others useful as they set their course toward successful, self-determined lives.

Define success for yourself.

People define success in many ways. Several successful people with disabilities use these words:

- *Success is defined by who we are, what we believe in, and what we think it means to be "successful." For some it is money; for others, relationships; for others, it's family; for others, it's jobs, for some it is religion, and for others it is education. I believe that success is reaching my own personal dreams. I'm not done with my dreams, but know that I have been successful so far because I've worked toward my goals regardless of my disability. (college student who is deaf)*
- *Success is possessing the capability for self-determination. Self determination is the ability to decide what I want to do with my life, and then to act on that decision. (high school student who is blind)*

- *A successful life is one where I can be actively engaged in creative activities that make a contribution to the lives of others. Success is a kind of bi-product and NOT an end in itself! (professor who is blind)*
- *To me, having a successful life is being able to do things independently for myself, and not always have someone there to do things for me. It's achieving my goals on my own terms and at my own pace. (high school student with mobility/ orthopedic impairment)*

Set personal, academic, and career goals. Keep your expectations high.

Successful young people and adults share their views below about how they set goals and maintain high expectations:

- *A combination of people and events has helped me maintain high standards. This all started during the summer months when my mother and neighbor friend pushed me to improve my academic skills. At the time it wasn't high standards that I was working for, but rather escaping embarrassment. For me, I wanted no one to know I had a disability and would have done most anything to hide it. These summer study sessions provided a stepping stone for future success in high school and college. Success builds upon itself. This was my start to expecting to do well in school.*
- *I'm just stubborn and I refuse to lower my expectations. (college student with a mobility/ orthopedic impairment)*
- *My parents helped me maintain high expectations for myself. They taught me never to say "I can't" at anything I try. (high school student with cerebral palsy)*
- *My mobility teacher made me confident in my ability to learn, which has helped me maintain high expectations. (college student who is blind)*
- *My parents expected me to do as well as other students without disabilities, if not better. My parents actively sought help for my hearing impairment in the forms of speech therapists, audiologists, and teachers to make sure that I had an equal chance in public schools. Before choosing a new house, my parents did a lot of research on the local schools. (college student who is deaf)*
- *My brother and sister had one single expectation that determined my success: I was not treated differently in any way because I could not see. (computer scientist who is blind)*
- *I am still in the process of learning to "stretch" but I start by identifying what I can already do - what I am comfortable doing and feel good at. Then I say to myself (sometimes in writing) I can do more. I can do better, what is it BEYOND what I already can do that I want to be able to do? Then I write down goals or ideas and make efforts to "stretch" myself. (adult with hearing and mobility impairments)*
- *Very early on, I became the stubborn guy I am today. "Can't" wasn't in my vocabulary, which, of course, was helped by a set of parents who offered me opportunities to do most of the things everyone else did and encouraged me to set very high standards. By now, I do realize that everyone has a path in life that their unique set of talents and lack thereof gives them. I will never be mistaken for an athlete. However, knowing what talents I do have, I press myself to be the best historian/philosopher/writer that I can be. (college student with a mobility impairment)*
- *I set personal, academic, and/or career goals by knowing where my limits are and working around them. If someone says I can't do something, and I haven't tried it before, that just makes me more determined to prove that someone wrong. If I fail, at least I tried. That's what counts. (college students with mobility impairments)*
- *One of the main reasons people do not set high expectations is fear of failure.... start by having achievable goals that are not long-term. Instead, develop week long, achievable goals that lead to success. Build on each success and make each goal a little higher. Think of it as a metaphorical high jump. You cannot set the bar too high in the beginning or you just set yourself up for failure. (adult with hearing and mobility impairments)*

Understand your abilities and disabilities. Play to your strengths.

People with disabilities who consider themselves successful generally accept their disabilities as one aspect of who they are, do not define themselves by their disabilities, recognize that they are not responsible for their disabilities, and know that they are not inherently impaired. They recognize their responsibility for their own happiness and future. Below are insights from successful people with disabilities:

- *My personal opinion about disabilities is that everyone is disabled. It just so happens that there is a certain group whose disabilities are more obvious than others. (high school student with mobility and visual impairments)*
- *My parents helped me learn to accept responsibility for myself by treating me the same as my siblings. They gave me the same punishments and chores, and they expected me to do well in school. (high school student with speech, hearing and mobility/orthopedic impairments)*
- *Do not make people feel sorry for you or pity you. Get people to view you as an able person who is capable of anything within your reach if the doors of opportunity are open. (graduate student with a hearing impairment)*
- *Clearly disabilities can be obstacles. However, they ought to be focused on as obstacles which problem solving can surmount. Sometimes, trade-offs do exist. I once wanted to go into biochemistry, but my lack of fine-motor skills and general distrust of lab partners made me realize that I wanted something I could do on my own - hence, history-philosophy. Perhaps I could have found adaptive technology to help me in biology and chemistry, but I had other loves as well, so I went for them. Admittedly, I rerouted, but for those who are determined to be biochemists and such, most obstacles can be overcome by abilities. (college student with mobility impairment)*
- *Focus on the ABILITY in disability more than the dis. If we can do that, then we are more apt to succeed. Also, know your limits. If you don't know what you can or can't do, how do you expect other people to know? Plan for success by using more of the cans than the can'ts. (college student with mobility impairment)*

Develop strategies to meet your goals.

Successful people use creative strategies to reach their goals. They look at options and make informed decisions. Successful planning requires that you know your rights and responsibilities and strengths and challenges; set goals; work toward those goals; and use tools and resources available to you. One key skill for success is self-advocacy. Being able to self-advocate requires that a young person become an expert on their disability, know what specific services and help they need, and be able to use strategies to obtain this help and support. One's life should not be defined by the assumptions of others. Insights by successful people with disabilities are shared below.

- *There is a difference between being the recipient of an act ("victimized") and allowing yourself to become overly affected by that act - i.e., to become a "victim." (adult with mobility/orthopedic impairment)*
- *We don't have to be "victims" of other people's assumptions. We are only victims if we choose not to take charge of a situation. If you are blind and someone grabs your arm and pushes you across the street and you don't say anything, but would like to, then you are letting the other person force the result of his assumptions on you. If you, on the other hand, either say, "thank you, but I'll be fine" or "let me take your arm," depending on what you would like to do, then you are taking charge and aren't a victim. (adult who is blind)*
- *I could never achieve anything without writing things down. Sometimes I use a calendar, sometimes a blank sheet of paper or my notebook, and sometimes the computer. But without putting my plans on paper, I am not able to get*

things done. I use a prioritization process. I write out everything that I need to do - including the small things like getting dressed, taking medications, and riding the bus. Then I mark the things that must get done today or tomorrow as opposed to later, and I prioritize in order of importance. The list I make is constantly changing but I get a lot of satisfaction crossing off accomplished steps. It also helps me to break down larger tasks into smaller ones. I make lists, plan how to do the things on the lists, then use the lists to motivate me to get things done. Never leave home without it! (adult with mobility and hearing impairments)

- *The more often I express my needs and preferences, the easier it becomes, and the easier it becomes, the more comfortable I am, and that makes people more comfortable, and on and on and on... and somewhere in the midst of this is the need to be both polite and clear. (adult who is deaf)*
- *The way to preempt or erase assumptions is to tell people what you need rather than let them "act out" what they think you need. It is okay to say what you need help with. I think that is part of being independent. And just by being out and about and going about your normal business you also show people what you don't need help with. (adult who is blind)*

Use technology as an empowering tool.

Being technologically competent has become an avenue to academic and career success. Computer technology is one of the most powerful tools available to individuals with disabilities. Technology, including computers, adaptive technology and the Internet, can help maximize independence, productivity and participation. It can lead to high levels of success – personally, socially, academically, and professionally. As reported by successful individuals with disabilities:

- *The computer helps me organize my thoughts. I can read and make improvements with ease. I can check all of my papers for spelling errors before I send them. I am a really BAD speller. (high school student with a learning disability)*
- *I use a combination of a palmtop note-taker computer and a desktop computer to write. Without them I'd be lost. (college student with mobility/health impairment)*
- *Without computers or the Net I would not be doing many things that I'm doing today. For instance, I am involved in a writing forum on the Net that lets writers talk about writing and share their pieces of literature with each other. Since I want to be a writer this has been VERY helpful. (high school student with a Dyslexia and Attention Deficit Disorder)*
- *One of my two or three best friends – maybe best next to my wife – and I met on the Internet, and we are not only friends but close working colleagues. (professor who is blind)*
- *Technology is not a nicety; it is a necessity. Get it, learn it and use it. (college student who is blind)*

Work hard. Persevere. Be flexible.

Knowing and valuing yourself, setting goals, and planning help build important foundations, but action is required to make your dreams come true. To take control of your life, it is necessary to choose and take appropriate action. Take charge. Move forward. Sometimes students with disabilities need to work harder to achieve the same level of success as their peers. As reported by one student who is blind:

I accepted the fact that I must work harder than other students to get the same grade.

But, learning to work hard has a positive side:

Sometimes I think that all of us with disabilities have an advantage over those who have things come easier to them. Whatever it is we want, we have to want it and then work for it. That necessary desire promotes drive to accomplish, succeed, or achieve. Others around us may be content to float, or do the minimum most of the

time, but not for us. For us, having what everybody else has is an accomplishment, and having tasted success we want to keep succeeding.

The willingness to take risks is critical to achieving success. As reported by one young person with a mobility impairment:

I keep going when people tell me I can't. I am not afraid to try things and I don't give up. My parents took me everywhere and I did everything like a normal kid. I have a good friend from kindergarten who is able bodied, and she knows me so well that we do all sorts of stuff that people might not think I could do, but we come up with a flexible plan and we do it.

Advice about risk taking from successful people with disabilities includes:

- *Nothing worthwhile comes without risk. Without risk, success cannot be achieved.*
- *Never give up.*
- *Do not pity yourself for what cards you have been dealt. It happened… now move on.*
- *That moment of insecurity is worth the achievement in the end. It is important to keep that in mind throughout life.*

Develop a support network. Look to family, friends, and teachers.

Successful adults with disabilities report that they were supported in youth by opportunities for inclusion, high expectations from adults, disability-related accommodations that de-emphasized their differences, promotion of autonomy, encouragement of friendships, and support from caring adults. On the other hand, their progress was inhibited by segregation, treatment that highlighted their differences, restricted opportunities for independence, social isolation and social rejection.

Below, successful individuals with disabilities share examples of how they stay actively involved.

- *I am in my school's band and on our Youth Leadership Team. In the past, I was part of the speech team and Student Council. I think being a part of clubs has given me confidence and boosted my self-esteem. I enjoy music, and think it is an awesome feeling to be able to go out and be a part of my school's band to cheer on the sports teams and to contribute to a music concert. (college student who is blind)*
- *I have been involved in the drama club at my school. (high school student who uses a wheelchair for mobility)*
- *I have been involved in internships. They give me experiences that are needed for jobs. I've also been part of a city hall committee. This will help me know how professional life is. (college student with mobility/health impairment)*

No one achieves success alone. The comments below provide examples of how successful individuals with disabilities have found, accessed, and used resources to help them achieve success personally, socially, academically, and professionally.

- *Most of the resources I use I either found through word of mouth (from parents, friends, and others I know), from newsletters, or from the Internet. Sometimes, I find out about something useful by accident, and at other times I ask around or look on the Internet for a specific resource. I often ask others whose opinion I respect for advice, especially when I am making a making a major decision. I subscribe to a few newsletters and magazines that provide information on topics that interest me and keep lists of useful Web sites on my home page. (Ph.D. Candidate who is blind)*
- *I ask questions. (high school student with a brain injury)*
- *One of my resources is my best friend. When I take her along with me, I can tell that people who don't know me feel comfortable being around me. My friend and I think that there isn't a way that I can't be a part of what she is doing. Being with her is one of the ways I use a natural resource. (high school student with mobility/orthopedic and speech impairments)*

Videotape

This brochure summarizes content that is covered in the DO-IT videotape. *Taking Charge: Stories of Success and Self-Determination.* The 17-minute videotape can be purchased by sending $25 to DO-IT. **Permission is granted to reproduce DO-IT videotapes for educational, non-commercial purposes as long as the source is acknowledged.**

Grants and gifts fund DO-IT publications, videotapes, and programs to support the academic and career success of people with disabilities. Contribute today by sending a check to DO-IT, Box 355670, University of Washington, Seattle, WA 98195-5670.

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For more information, to be placed on the mailing list, or to request materials in an alternate format, contact:

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